Living Well with Chronic Conditions

Self-Management Resource Center

Utah Arthritis Program: **Implementation Guide**

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UTAH DEPARTMENT OF HEALTH

Utah Arthritis Program

This handbook has been developed as a guide for coordinators of the Living Well with Chronic Conditions Program in Utah. Much of the information has been taken from the Self-Management Resource Center's Coordinator Handbook. A detailed program implementation guide is it at:
http://www.selfmanagementresource.com/

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I. Program Description

Background

The Chronic Disease Self-Management Education (CDSME) programs were originally developed at Stanford University, Palo Alto, CA, but are now under the Self-Management Resource Center (SMRC). In Utah, they are known as the Living Well with Chronic Conditions Programs and includes Living Well with Chronic Pain (CPSMP), Living Well with Diabetes (DSMP), Tomando Control de Su Salud (Spanish CDSMP or Tomando), and Programa de Manejo Personal de la Diabetes (Spanish DSMP or Manejo).

CDSME workshops are six week programs for people with chronic conditions, their caregivers, and their significant others. The two and a half hour workshop is provided once a week, for six weeks, and is held in community settings such as senior centers, churches, libraries, clinics, and hospitals. Workshops are facilitated by two trained Peer Leaders, one or both of whom are non-health professionals with at least one chronic condition.

People who attend the workshops may have one or more chronic conditions, but they all benefit due to the topics: 1) techniques to deal with problems such as frustration, fatigue, pain and isolation, 2) appropriate exercise for maintaining and improving strength, flexibility, and endurance, 3) appropriate use of medications, 4) communicating effectively with family, friends, and health care professionals, 5) nutrition, and, 6) how to evaluate new treatments. Emphasis is placed on three skills: action-planning, disease related problem solving, and decision-making.

The program developers have scripted the course content and have specified time frames for each activity conducted during the sessions. The course is to be taught as written in order to maintain the fidelity of the program. SMRC staff members revise this manual approximately every five years. Their changes take into account suggestions from Peer Leaders, Master Trainers, program coordinators and program participants. Sometimes there are special reasons to change the program in small ways. Before these are undertaken, permission from SMRC must be granted by emailing them directly.

Each participant should receive printed materials during the course of the workshop. More information about this is addressed in the Materials section.

II. Program Needs

Program Coordinator

Every organization needs to have at least one program coordinator. The program coordinator recruits and supervises leaders, arranges for workshop sites, maintains program fidelity, and may conduct program evaluation. This is also the person that leaders turn to in an emergency. This person may have received leader training and/or training as a Master Trainer, however it's not required a coordinator. See the **Living Well Coordinator Description** (Fidelity Document I) for further details on roles and responsibilities of a Living Well Coordinator.

III. Peer Leaders

How to Recruit Peer Leaders

Implementation of the program requires **two** trained Peer Leaders for each six-week workshop. Peer Leaders do not have to be experts or have professional experience. Laypersons usually make excellent leaders, especially if at least one of them has a chronic health condition. In some cases both leaders are volunteers receiving no pay, but it is suggested that leaders receive a small stipend ($150 to $200 total for teaching a six-week program).

The job of the leader is to teach the six-week workshop using the detailed scripted manual provided in their training. Leaders are expected to show up on time for classes prepared to teach throughout the full workshop. See the **Peer Leader Position Description** (Fidelity Document II) for a more detailed description of Peer Leader roles and responsibilities. Successful Peer Leaders are leaders who are:

- Effective communicators and respectful in group settings
- Self-aware and ethical
- Committed to personal growth
- Approachable and sincere
- Welcoming to people from diverse backgrounds

You probably already know people who would make great Peer Leaders. Look around your own community settings and talk to people about this opportunity to gauge interest and capability. Ask your Peer Leaders to watch for people in their classes who they think might make great Peer Leaders and then have the Peer Leaders approach them about it at an appropriate time. You may find it helpful to have people interested in becoming a Peer Leader complete the **Peer Leader Application** (Fidelity Document III)

How Are Leaders Trained?

All Peer Leaders must attend a six hours per day training for four days taught by a Master Trainer to be certified to teach a program. They must attend all of the training. Before sending a potential leader to training, he/she must complete both a **Peer Leader Agreement** and **Non-Disclosure Form** (Fidelity Documents V & VI) and submit them to their coordinator. It is best if the workshop(s) they are to teach is/are already planned with dates, sites, and recruitment if possible, before they are trained. A trained Peer Leader is required to lead a workshop within the first twelve months following the training to remain certified. If any Peer Leader goes more than twelve months without teaching a workshop, they will have to go through all four days of the Peer Leader training again to become recertified.

How Are Leaders Monitored?

Monitoring the leaders is a key component in program implementation, especially to preserve program fidelity.

- Leaders always teach in pairs. This is true even if the leaders have a great deal of experience.
- New leaders are best paired with experienced leaders. This is not always possible but should be done when possible.
- A new leader is to be observed by a Master Trainer during his/her first workshop during either the 3rd, 4th, or 5th session. This way you can assure the new leader is teaching according to fidelity and identify any problem areas. If any arise, there should be follow up immediately.
- A check-in call can be made to the leaders after the fourth or fifth class. Problems are often uncovered and resolved with these calls.
- If at all possible, leaders should periodically be observed in person. An observation should definitely be done if an issue with Peer Leaders arises. This is best done at the 3rd, 4th, or 5th session so there will be time for leaders to utilize feedback. When observing leaders, use the **Workshop Fidelity Checklist** (Fidelity Document IX)

IV. Organizing Workshops

Recruiting Participants

Workshops with ten to twelve participants are most productive. Workshops with less than eight participants often fail to achieve group cohesiveness and cannot provide consistent peer support. Over time, successful programs have generated additional consumer interest through outreach efforts such as:

- Conducting community presentations
- Distributing program materials, such as brochures, fact sheets, and flyers to various community agencies
- Submitting a news release to local newspapers and/or public service announcements to radio/TV stations
- Conducting media presentations or interviews
- Compiling a mailing list or email distribution list
- Talking with potential leaders
- Using physician referrals in a clinic or healthcare setting
- Using Compass to provide consistent scheduling

After potential participants have been identified or registered for the workshop, the Peer Leader should:

- Send a brief introductory email that describes the workshop
- Call each participant to ask about his/her availability to attend, accessibility of the meeting location, need for an interpreter or other assistive technology, and need for accessible transportation
- Arrange transportation and assistive technology as needed
- Send a final email that lists the meeting times and location, contact information, and any other pertinent details

Workshop Location

Hold workshops in places where people in your target audience usually go- familiar sites are more successful than unfamiliar sites. Arranging an accessible meeting space for sessions is critical to organizing a Living Well workshop. “Accessible” generally means that people with any type of disability can get to, in, around, and out of a building and meeting room. It also means they can use the building’s facilities, such as the bathroom. Program sites should meet the following criteria:

- Handicap accessible
- Have safe, ample parking
- Be able to accommodate up to 20 people in a circle or configuration
- Be open to having anyone from the community attend

- Have a room that provides privacy and enough space for the leaders, participants, flip charts, white board, and room to move around
- Be located in the same community you want to serve for easy accessibility for participants

The following is a list of some sites that many groups have found useful:

- Senior centers
- Public libraries
- Churches
- Community centers
- Community rooms in hospitals

Prepare for the First Meeting

Accessible rooms can become inaccessible if the furniture is poorly arranged. On the day of the first session, the Peer Leader should arrive at least 30 minutes early to ensure everything is prepared and satisfactory.

Workshop participants are diverse individuals with diverse learning needs. Peer Leaders should supply the learning tools and resources that each participant needs to be successful. Some participants may have already requested workbooks in alternative formats or assistive technology, which should be in place. Others may request help with turning workbook pages or writing down exercises.

V. Materials

Books and CDs are available from Bull Publishing. All other materials are purchased locally.

1-800-676-2855

http://www.bullpub.com

P.O. Box 1377, Boulder, Colorado 80306

Each participant in the English program will need:

- A copy of the book *Living a Health Life with Chronic Conditions.* (Please note that this is available in several languages and there are also English editions for the United States, Canada and the United Kingdom.) For those who cannot read or see this is also available on CD.
- A relaxation CD (this is optional but many participants find it useful)

Each participant in the Spanish program (Tomando Control de Su Salud) will need:

- A copy of the book *Tomando Control de Su Salud*
- An exercise CD (audio) in Spanish
- A relaxation CD in Spanish (this is optional but many participants find it useful)

An organization is responsible for the cost of the workshop supplies, unless stated otherwise in their contract.

Other workshop supplies needed include paper, pens, pencils, easels, etc. Please refer to the **Workshop Materials Checklist** (Fidelity Document XI) for the full list of supplies a Peer Leader may need for each workshop.

VI. Costs

Implementation costs vary. There are many factors, depending on how many programs you will implement, that will determine costs. Some cost considerations include but are not limited to:

- Program License (no cost if under statewide license, for now)
- Peer Leader stipend (if offered and accepted)
- Peer Leader training (no cost if under statewide license, for now)
- Sites for workshops (usually donated but you may have to consider rent)
- Materials for participants, such as books (if choose to buy instead of print)
- Workshop supplies; consider whether you want to use whiteboards, flipcharts, scratch paper, pens and pencils.
- Optional light, healthy snacks (Ex., fruit, cheese, etc.)

Your organization should discuss the method you would like to use to ensure that workshop materials are available to participants.

VII. Utah Department of Health, Arthritis Program Reporting

The Utah Arthritis Program requires that the following forms are completed and entered in Compass (secure data management system) after each workshop: (Fidelity Documents VII & VIII).

- Workshop Attendance Form
- Participant Information Forms (PIF)

VIII. Data Security Training and Protocols

The Privacy Act of 1974 protects records that can be retrieved by personal identifiers such as a name, social security number, or other identifying number or symbol. It was created in response to concerns about how the use of computerized databases might impact individuals' privacy rights.

- It requires government agencies to show individuals any records kept on them

- It requires agencies to follow "fair information practices" when gathering and handling personal data.
- It places restrictions on how agencies can share an individual's data with other people and agencies.
- It lets individuals sue the government for violating of these provisions

Both coordinators and Peer Leaders are responsible for protecting Personal Identifiable Information (PII) and letting participants know of their rights when collecting their information such as in the attendance and participant information forms.

This requires coordinators, Peer Leaders, and any data-entry persons to *properly* collect, handle, transport, enter and store or destroy data collected on workshop participants. This entails following the protocols outlined below:

- All coordinators, Peer Leaders, and any data-entry persons must sign non-disclosure agreements.
- Non-disclosure agreements must be submitted to UAP in order to be registered in Peer Leader Trainings OR for those not participating in Peer Leader trainings (e.g. data-entry users), agreements must be submitted before any collection or handling of data.

No agency or person shall disclose any record, by any means of communication, to any person or another agency, without a written request or prior written consent of the individual to whom the record pertains. “Any means of communication” includes oral (phone, in-person), written, and electronic (emails, faxes, texts, tweets, pins, etc.).

Collection of Program Forms

Peer leaders must read the **Peer Leader Script** (Fidelity Document IV) in order to get participant consent to collect and share the program forms with UAP. The Peer Leader Script is read before collecting the Participant Information Form (PIF) and ensures participants know participant privacy is protected and why data is collected, including stating that:

- The PIF is voluntary. They may skip any questions they do not want to answer and may choose to not complete the Survey, but they can still participate in the program
- Participant information will be treated in a safe and confidential manner
- Participant information forms are shared with the Utah Arthritis Program and its funding organizations/secure database contractors in order to improve and sustain the program

Storage Program Forms

- Store completed forms in sealed envelope if mailing to the program coordinator
- Store completed forms in a secure, locked cabinet when not in use

- Enter data into Compass within 10 days of workshop completion
- Maintain forms in secure, locked location for up to three years in case of the need for data verification
- Destroy old data forms using methods that render the information unrecognizable or beyond reconstruction (e.g. shredding, burning, pulping, melting, deleting/emptying recycle bin, etc.).

Safe Transportation of Forms

- Hand carrying
    - Use a cover sheet to shield contents
- Using mail
    - Use manila or white envelopes
    - Mark the envelope to the attention of the authorized recipient
    - Never indicate on the outer envelope that it contains PII
- Using email
    - Password protect personal data placed on shared drives, the Internet, or the Intranet
    - Use encrypted email
    - Do not send PII to a personal, home, or unencrypted e-mail address
    - Announce in the opening line of the text (NOT the subject line) that FOUO information is contained

Safeguarding Personally Identifiable Information

- Must always be treated as "FOR OFFICIAL USE ONLY" and must be marked accordingly
- Applies not only to paper records but also includes email, faxes, etc., which must contain the cautionary marking "FOR OFFICIAL USE ONLY – FOUO"
- Should be stored in locked filing cabinets or other secure containers to prevent unauthorized access
- Must be password protected when it's in electronic records and must be transferred via encrypted email

Personally Identifiable Information

"The term Personally Identifiable Information means any information about an individual maintained by an agency, including, but not limited to, education, financial transactions, medical history, and criminal or employment history and information which can be used to distinguish or trace an individual's identity, such as their name, social security number, date and place of birth, mother's maiden name, biometric records, etc., including any other personal information which is linked or linkable to an individual."
http://www.gsa.gov/portal/content/104256

Personally Identifiable Information (PII) includes:

- Home address
- Home telephone number
- Complete date of birth
- Personal medical information
- Social Security Number (including just the last four digits of SSN)
- Personal/private information (if the information can uniquely identify the individual)
- Photographs

Data Security Roles and Responsibilities Summary

- Take privacy protection seriously
- Respect the privacy of others
- Ensure messages, faxes, and emails that contain personal information are properly marked and email is encrypted
- Don't share PII with individuals who are not authorized
- Have appropriate transfer, storage, and disposal protocols in place for PII
- Do not email PII to personal, home, or unencrypted accounts
- Read the Peer Leader Script to advise all participants of their right to consent or refuse use of data about them
- Complete and submit non-disclosure agreements before handling program forms/data

IX. Need Additional Support?

If you have questions that your Living Well Coordinator cannot answer, contact the UAP:

Program website:

www.health.utah.gov/arthritis/

Program search website:

http://livingwell.utah.gov/

UAP Staff and associated responsibilities:

Nichole Shepard
Program Manager (Contracts, Invoices, Partnerships)
nshepard@utah.gov or (801) 538-6259

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